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ORIGINAL ARTICLE

Attitudes to prenatal diagnosis and termination of pregnancy for fetal abnormalities in Saudi couples: a single center experience

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ABSTRACT

Background: Prenatal diagnosis (PND) is an effective method for early detection of genetics and hereditary diseases during pregnancy in order to help the couple to take the proper decision regarding affected fetus. The current study aimed at assessing the attitude of Saudi couple regarding prenatal diagnosis and termination of pregnancy (TOP) for fetal abnormalities.

Methodology: A descriptive cross-sectional was carried out; 100 couples attended Genetic Clinics in King Abdullah Specialized Children's Hospital in Riyadh, who were interviewed using an questionnaire consisting of four parts covering socio-demographic data of participants, family & obstetric history, knowledge, and attitude of couples regarding PND and TOP. Descriptive statistics and chi-square tests were used for data analysis.

Results: The results of the study showed that the mean age of fathers were 38.8± 8.1 years, while the mean age of mothers were 33.9 ± 6.9 and most of the couples (93%) lived in the urban area. Among them, 47% of couples had a positive family history of genetic diseases; 16% of mothers performed PND in their previous pregnancies. Among them, 62% and 76% of fathers and mothers, respectively, had satisfactory knowledge about PND and TOP with a statistically significant difference between them.

Conclusion: A comprehensive genetic counselling service offered to the couples may influence the decision on TOP. The awareness about PND and TOP is crucial to obtain good understanding and positive future strategies.

Keywords: Prenatal diagnosis, termination of pregnancy, fetal abnormalities, Saudi couples, attitude.

Introduction

Early detection is one of the cornerstones of disease prevention, prenatal diagnosis (PND) is important in the early detection of genetic diseases, which reduce the incidence of these diseases. PND refers to several methods used to identify the genetic conditions before birth or conception known to affect the neonate (1). According to Carlson and Vora (2), prenatal diagnosis is referred to diagnosis before birth; methods which used for prenatal diagnosis include ultrasound of the uterus, placenta, and/or developing fetus; chorionic villus sampling to obtain tissue for chromosome or biochemical analysis; and amniocentesis to obtain amniotic fluid for the analysis of chromosomes, enzymes, or DNA. A growing number of birth defects and diseases can be diagnosed prenatally and, in some cases, treated before birth. The purpose of PND is to provide prenatal diagnostic testing services (for genetic conditions) that enable families to make informed choices consistent with their individual needs and values and supporting them to deal with the outcome of such testing (3). PND raises ethical dilemmas such as the option of termination of pregnancy (TOP) in cases with severe outcomes. In Saudi Arabia, there has been a continuous debate on TOP, and the laws have evolved only marginally over the last few decades. In early 2011, The Standing Committee for Scientific Research and Ifta (SC) in Saudi Arabia issued an edict (Fatwa no. 240 dated 16 January 2011) legalizing abortion in

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certain circumstances (4). The decision to terminate an affected fetus may be influenced by a variety of factors, such as the country's laws and health system, as well as the parental level of education, socioeconomic status, religious, and cultural beliefs (5). Previous studies have explored the public's opinion of genetic testing and how the characteristics of genetic disorders might influence people's attitudes toward prenatal genetic screening and termination of pregnancy (TOP) (6,7). Attitudes toward requested TOP, because of either possible fetal abnormality (selective TOP) or for social reasons, and its regulation varies from country to country (8). The same tension between strong acceptance of the idea of prenatal diagnosis and salient refusal of abortion is also evidenced in Saudi Arabia (9).

Subjects and Methods

The study aimed to assess the attitude of the Saudi couple regarding prenatal diagnosis and termination of pregnancy for fetal abnormalities. a descriptive cross-sectional design was used; 100 couples attended Genetic Clinics in King Abdullah Specialized Children's Hospital in Riyadh were interviewed using an interviewing questionnaire which consists of four parts covered socio-demographic data of participants, family & obstetric history, knowledge, and attitude of couples regarding PND and TOP (Figure 1). Descriptive statistics and chi-square tests were used for the data analysis. Informed consent was obtained from each couple participated in the study. This study was approved by the Institutional Review Board at King Abdullah International Medical Research Center (KIMARC) (Study number: RC19/109/R). The study included: 1) All Saudi couples who had a child with a genetic disease and who visited Genetic Clinics (GC) in King Abdullah Specialized Children's Hospital (KASCH) in Riyadh, Saudi Arabia and accepted to participate in the study. 2) Saudi couples or mothers who had come to GC in KASCH and had prenatal testing and termination of pregnancy. 3) Saudi couples or mother who had come to GC in KASCH and had prenatal testing and refused to termination of pregnancy (Table 3). The study excluded non-Saudi couples who attended GC in KASCH hospital. The data were analyzed using the Statistical Package for Social Sciences (SPSS) Version 20. For descriptive statistical analysis; frequencies and percentages were used for all variables included in the study to describe the demographic data and explore the knowledge and attitude of couples, arithmetic means and standard deviations are also used. For inferential analysis, the Chi-Square test was used to examine the

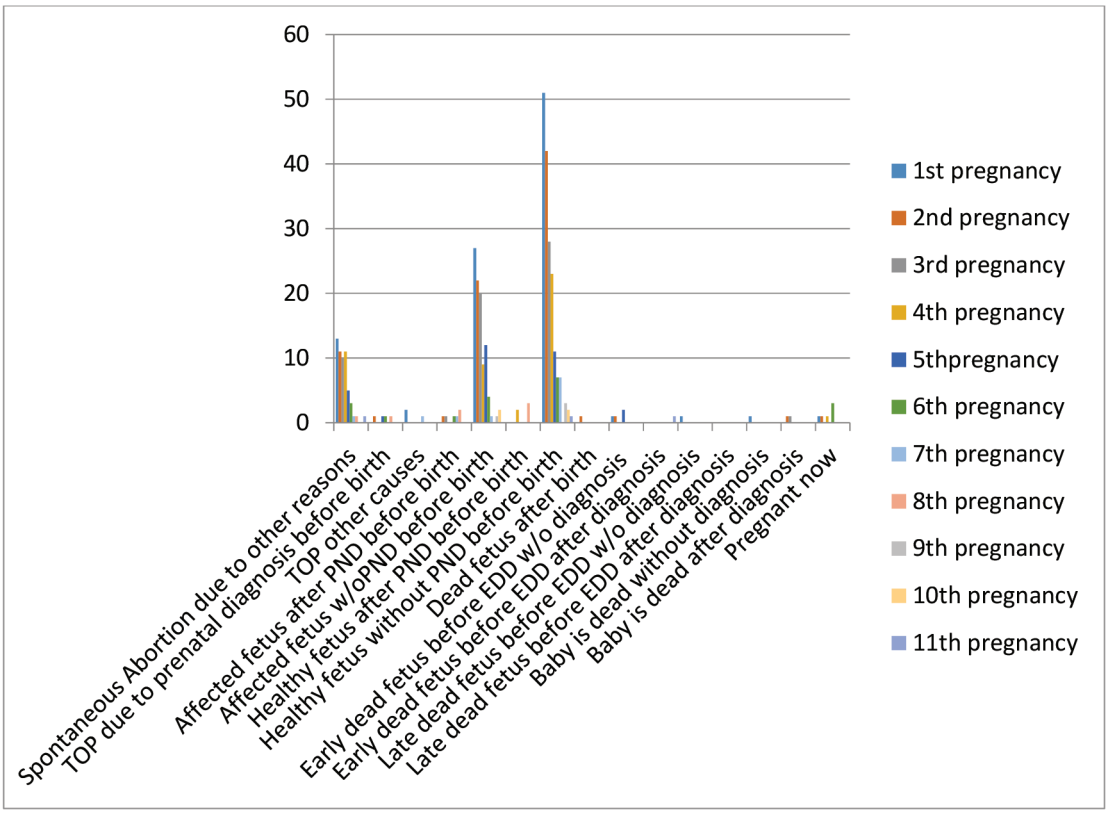

Figure 1. *Distribution of mothers according to the outcome of each pregnancy. This illustrated the outcome of each pregnancy for mothers. It showed that the most common outcome between pregnancies was healthy fetus without prenatal diagnosis before birth followed by an affected fetus without prenatal diagnosis then a spontaneous abortion due to other reasons.*

relation and association between variables. The statistical test of significance, or *p*-value, in this study, was set at <0.05. The internal consistency of the tool was measured by calculating the Cronbach's alpha.

Results

The mean age of fathers was 38.8± 8.1 years, while the mean age of mothers was 33.9 ± 6.9. In terms of educational level, about half of fathers and mothers (50% and 57%), respectively, had a high school level. Turning to a residence, most couples (93%) live in the urban area. Regarding monthly income; more than one third (41%) of couples their income were ranged between 5,000 to < 10,000 (Table 1). Consanguinity was found in 69% of the couples. 75.4% were first cousin. 47% had positive family history to the genetic diseases, and 43% still under investigations about 74% of them had one affected child within the family, 15% had two affected children and only 1% had three affected children within the family. Regarding mode of inheritance about 57.4% was recessive, 2% autosomal dominant, and 2% X-linked, while 31% does not know exactly the mode of inheritance (Table 2). The knowledge of couples regarding PND and TOP; about 55% and 78% of fathers and mothers had information about PND and TOP, respectively. A significant difference between fathers and mothers presented (Figure 2). Approximately, 76.3% and 58.9% of fathers and mothers their sources of information were physicians, respectively. Regarding information about Fatwa which legalizing abortion in certain circumstances; 76% and 82% of fathers and mothers, respectively, had information about it and 56% and 67% of fathers and mothers, respectively,

Table 1. *Distribution of couples according sociodemographic characteristics*

Items	Fathers (*n* = 100)	Mothers (*n* = 100)
Age (years)		
18–25	3	6
26–35	38	57
36–45	41	29
>45	18	8
Mean ± SD	38.8 ± 8.1	33.9 ± 6.9
Educational level		
Illiterate	0	1
Basic education	7	17
Secondary school	43	25
High school	50	57
Residence		
Rural	7	
Urban	93	
Monthly income (SR)		
<5,000	13	
5,000 to less than 10,000	41	
10,000 to less than 15,000	22	
>15,000	24	

This table shows a socio-demographic data of couples; the mean age of fathers was 38.8 ± 8.1 years, while mean age of mothers was 33.9 ± 6.9. In terms of educational level; about half of fathers and mothers (50% and 57%), respectively, had a high school level. Turning to a residence, most of couples (93%) live in urban area. Regarding monthly income, more than one third (41%) of couples their income were ranged between 5,000 and < 10,000.

Table 2. *Distribution of couples according to family history.*

Items	Couples (*n* = 100)
Relatives relationship between couples	
Yes	69
No	15
Same tribe	16
Degree of relationship	**(*n* = 69)**
Close to first cousin	52 (75.4%)
Second cousin	15 (21.7%)
Distant relationship	2 (2.9%)
Identified genetic disease(s) within the family	
Yes	47
No	10
Under investigation	43
Number of affected children within the family	**(*n* = 90)**
1	74
2	15
3	1
Mode of inheritance	**(*n* = 47)**
Dominant	1(2.1%)
Recessive	27 (57.4%)
New mutation, very low recurrence	3 (6.4%)
Inheritance related to gender	1 (2.1%)
Don't know	15 (31.9%)

This table clarifies that about (69%) of couples were consanguineous and 75.4% were first cousin. In regards to identified genetic diseases within the family; about 47% had positive family history to the genetic diseases, and 43% still under investigation about 74% of them had one affected child within the family and only 1% had three affected child within the family. Regarding to mode of inheritance about (57.4%) was recessive.

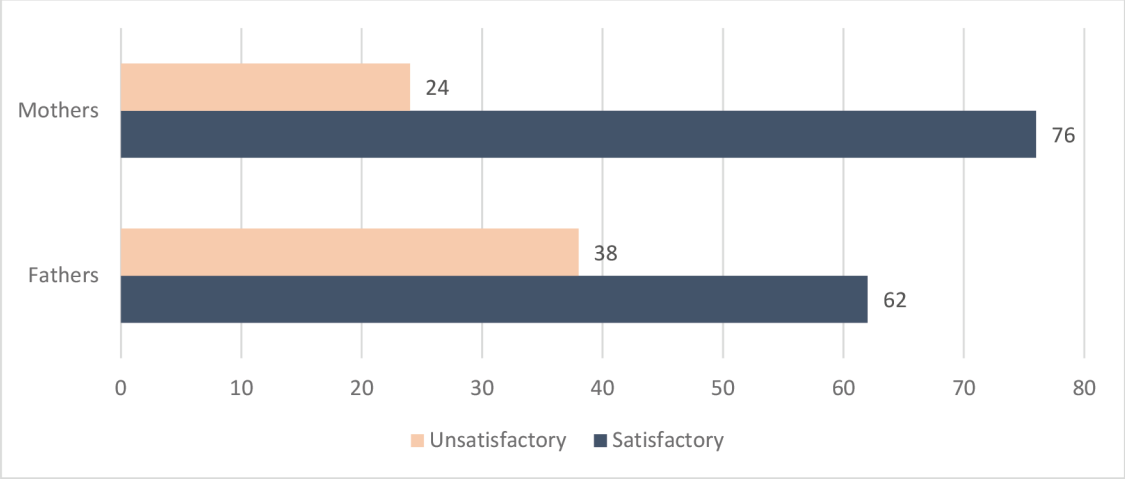

Figure 2. *Distribution of couples according to total score of knowledge: showed that (62% and 76%) of fathers and mothers respectively had satisfactory knowledge about PND and TOP with statistically significant difference between fathers and mothers.*

Table 3. *Distribution of mothers according to obstetric history.*

Items	Mothers (*n* = 100)
Number of previous pregnancies	
1–3	51
4–6	34
>6	12
No pregnancy	3
Number of pregnancies after diagnosis of index case	**(*n*=47)**
Once	10 (21.3%)
Twice	6 (12.8%)
Three times	4 (8.5%)
None	27 (57.4%)
Performing PND or PGD	
Yes	16
No	84
Number of performing PND or PGD	**(*n*=16)**
1	10 (62.5%)
2	5 (31.3%)
3	1(6.3%)

This table concerns with obstetric history of mothers; it showed that 51% of mothers had previous pregnancy from one to three times and about 12% had more than six previous pregnancy, while only 3% had not previous pregnancy. About 57.4% had not pregnancy after diagnosis of index case and 21.3% had one pregnancy after diagnosis of index case. Regarding performing PND or PGD, the table showed that only (16%) of mothers did it and (62.5%) of them did it once.

had information about these certain circumstances. 62% and 76% of fathers and mothers, respectively, had satisfactory knowledge about PND and TOP with a statistically significant difference between fathers and mothers (Table 4). About 7% of fathers disagreed to do PND, while 57.1% of them completely rejected the idea of PND. 6% of mothers disagree to do PND, and 50% of them refuse due to religious causes. About 94% and 96% of fathers and mothers, respectively, agreed that the choice of PND is good and 53% and 56% of fathers and mothers, respectively, suggested that it should be a compulsory option. Regarding the TOP (61% and 63%) of fathers and mothers, respectively, agreed, whereas 14% of fathers disagreed, 57.1% of them refused due to religious causes. 8% of mother disagreed, 75% of them refused due to the same reason (religion). 81% and 85% of fathers and mothers, respectively, had a positive attitude regarding PND and TOP without statistically significant differences between both genders (Table 5) (Figure 3).

Discussion

It is well known that "prevention is better than curative." According to the study of Goldsteen, et al, 2015, primary prevention was defined as eliminating the risk factors for a disease while secondary prevention is focusing on early detection and treatment of disease (10). This study was performed to shed a light on the attitude of Saudi couples toward prenatal diagnosis and termination of pregnancy for fetal abnormalities. It focused on PND as an effective method for early detection of genetics and hereditary diseases during pregnancy and also TOP was considered as an option for fetal abnormalities. Although a wide range of scientific researches was conducted and advised against consanguineous marriage, as it considered one of the most common causes of genetic disease transmission, the main findings of this study showed of couples were consanguineous with a majority of first-degree relatives. Approximately, half of the samples 47% have positive family history to genetic diseases. This suggests that

Table 4. *Distribution of couples according to their knowledge about PND and TOP.*

Items	Fathers (*n* = 100)	Mothers (*n* = 100)	Chi	*p* value
Having a previous background about PND & TOP				
Yes	55	78	11.8	0.0005 **HS
No	45	22		
Resources of previous background	**(*n*=55)**	**(*n*=78)**		
Physicians	42 (76.3%)	46 (58.9%)		
Genetic counselors	2 (3.6%)	4 (2.1%)	4.33	0.23
Reading and Media	8 (14.5%)	23 (29.4%)		
Other resources	3 (5.5%)	5 (6.4%)		
Having previous background about Fatwa legalizing abortion in certain circumstances				
Yes	76	82	1.08	0.297
No	24	18		
Having previous background about certain circumstances which permit abortion				
Yes	56	67	2.55	0.11
No	44	33		
Total score of knowledge				
Satisfactory	62	76	4.58	*0.03 S
Unsatisfactory	38	24		

**p* value is significant at the < 0.05 level.
***p* value is highly significant at the level <0.001.
This table shows the knowledge of couples regarding PND and TOP; about 55% and 78% of fathers and mothers had information about PND and TOP respectively. A significant difference between fathers and mothers presented. Approximately, 76.3% and 58.9% of fathers and mothers their sources of information were physicians, respectively. Regarding information about Fatwa which legalizing abortion in certain circumstances; 76% and 82% of fathers and mothers, respectively, had information about it and 56% and 67% of fathers and mothers, respectively, had information about these certain circumstances.

could be due to the lack of knowledge and awareness in Saudi society. The study done by Al-Alaiyan and Alfaleh (11) recommended that PND should be a priority due to the high rate of consanguineous marriages among first cousins in Saudi Arabia and their association with congenital anomalies. The study done by Bittles (12) found a significant positive association has been consistently demonstrated between consanguinity and congenital defects with a complex etiology appear to be both more prevalent in consanguineous families and have a greater likelihood of recurrence. With regard to gender preference in this study, it appeared that male respondents were significantly have limited knowledge among couples about PND and TOP. On the contrary, mothers had more information regarding PND and TOP than fathers. This can due to several reasons; mothers are the ones who exposed to these procedures, so they read more about it. The study was done (13) recognized that mothers often attend alone for prenatal counseling sessions. It is imperative that genetic counseling services proactively encourage both fathers and mothers to attend their appointments so that counselors can inform and facilitate joint decision-making. Furthermore, counselors should acknowledge and meet the needs of fathers as individuals (14). Therefore, the genetic counselor must raise the awareness of the importance of the father to accompany to attend the session. In the present study, there was a moral equivalence between fathers and mothers thoughts regarding PND and TOP. This result in concurrence with (15) which stated that positive attitudes were found toward PND among the three groups surveyed in their study; Saudi, UK-Pakistani, UK-White women. Also, the study done by Alsulaiman and Hewison (16) showed that attitude toward prenatal diagnosis was highly favorable and very similar in fathers and mothers, However, the attitude toward the termination of pregnancy was more favorable in the mothers than in the fathers. A conflict occurred among the minority of couples in this study. Overall, a disagreement to undergo PND and TOP due to mostly religious causes. These results come in agreement with (17) which demonstrates that the factors that affect the decision-making for pregnant with congenital anomaly whether to abort or not are diverse and involve cultural and social aspects, but mainly religious considerations. Furthermore, studies of attitudes to PND and TOP conducted in Saudi Arabia which focused on

Table 5. *Distribution of couples according to their attitude regarding PND and TOP.*

Items	Fathers (*n* = 100)	Mothers (*n* = 100)	Chi	*p* value
Do you agree to do PND?				
Yes	93	94	0.08	0.77
No	7	6		
Causes of disagreement to do PND	**(*n*=7)**	**(*n*=6)**		
Religious causes	2 (28.6%)	3 (50%)		
Fear of examination and its complications	0 (0.0%)	1(16.7%)	2.81	0.42
Financial causes	0 (0.0%)	0 (0.0%)		
Refusal based on the opinion of husband / wife	1 (14.3%)	0 (0.0%)		
Complete rejection of the idea of examination	4 (57.1%)	2 (33.3%)		
The choice of PND				
Good	94	96	0.42	0.52
Bad	6	4		
From your opinion PND should be				
Compulsory	53	56	0.18	0.67
Optional	47	44		
Agreement of TOP				
Agree	61	63	1.96	0.4
Neutral	25	29		
Disagree	14	8		
Causes of disagreement to do TOP	**(*n*=14)**	**(*n*=8)**		
Religious causes	8 (57.1%)	6 (75%)		
Fear of abortion and its complications	0 (0.0%)	1 (12.5%)	7.18	0.06
Financial causes	0 (0.0%)	0 (0.0%)		
Refusal based on the opinion of husband / wife	0 (0.0%)	1 (12.5%)		
Complete rejection of the idea of abortion	6 (42.9%)	0 (0.0%)		
Total score of attitude				
Positive	81	85	0.56	0.45
Negative	19	15		

This table presents the attitude of couples toward PND and TOP; about 7% of fathers disagreed to do PND, while 57.1% of them completely rejected the idea of PND. 6% of mothers disagree to do PND, and 50% of them refuse due to religious causes. About 94% and 96% of fathers and mothers, respectively, agreed that the choice of PND is good and 53% and 56% of fathers and mothers, respectively, suggested that it should be a compulsory option. Regarding the TOP, 61% and 63% of fathers and mothers, respectively, agreed, whereas 14% of fathers disagreed, 57.1% of them refused due to religious causes. 8% of mother disagreed, 75% of them refused due to the same reason (religion).

parents' attitudes assumed that religious belief was the main factor that influenced parent's attitudes (18,19). Moreover, according to Alkuraya and Kilani (9) study that highlights that the attitude toward abortion was greatly affected by religious values. Education about religious ruling significantly affected parents' attitudes towards accepting abortion and prenatal diagnosis. However, it is of importance to increase the awareness of Islamic ethical and religious aspects to abortion, especially in severe cases. These data not necessarily directly reflect the Islamic values it might originate from cultural traditions. The present study found that most of fathers and mothers were agreed to do PND and TOP. Similar to other studies (16) parents of children with a recessive condition and their relatives were more accepting of PND than TOP for the majority of conditions while the study done by Ahmed et al. (13) claim that the fathers were more accepting of prenatal diagnosis and termination of pregnancy than the mothers this may be because the fathers believed they had overall responsibility of care for their family, or because they experience financial and societal pressures.

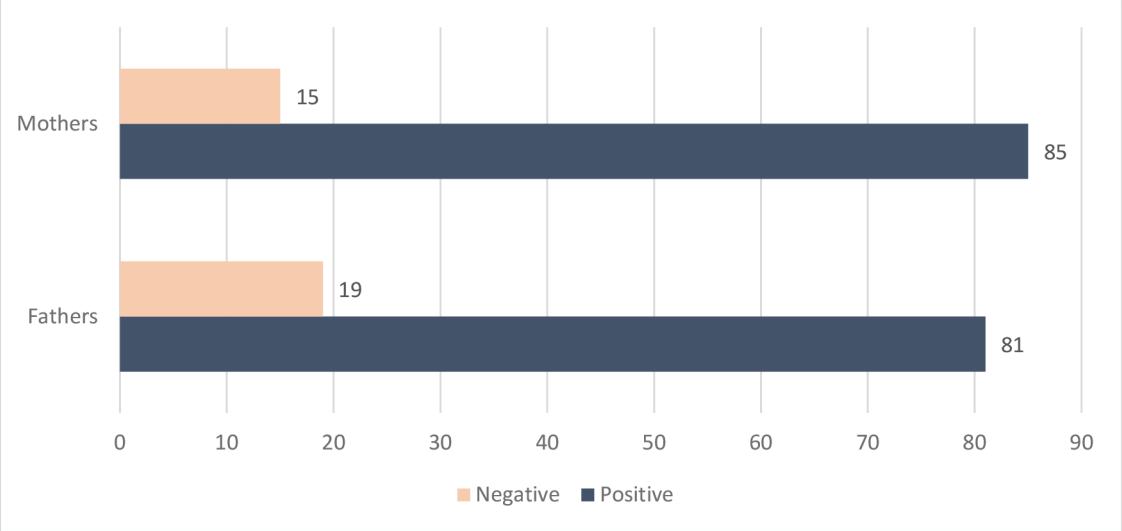

Figure 3. *Distribution of couples according to total score of Attitude: showed that (81% and 85%) of fathers and mothers respectively had positive attitude regarding PND and TOP without statistically significant difference between both genders.*

Conclusion

This study contributed to assess the attitude of Saudi parents toward prenatal testing for congenital anomalies and termination of affected pregnancy at King Abdullah Specialized Children's Hospital in Riyadh, Saudi Arabia, which was found to be positive in both fathers and mothers. The study concluded that fathers and mothers had satisfactory knowledge about PND and TOP with a statistically significant difference between fathers and mothers. The evidence-based regarding the attitude of Saudi parents toward PND and TOP still weak, so it's important to focus on factors which influence the attitude of parents toward PND and TOP such as availability of social services, genetic counseling, and rehabilitation centers, to obtain a deeper understanding of their attitude. Early prevention through PND is the preferred option for parents at risk of having an affected child with a genetic condition at King Abdullah Specialized Children's Hospital in Riyadh, Saudi Arabia. Females have significantly higher knowledge and a positive attitude towards PND and TOP than males. The most influencing factor that affected the parents' attitude where the accessibility to social services and rehabilitation centers. Moreover, comprehensive genetic counseling service offered to the couples may influence the decision on TOP. The awareness about PND and TOP is crucial to obtain a good understanding and positive future strategies.

List of Abbreviations

EDD	Estimated Date of Delivery
GC:	Genetic Clinic
KASCH	king Abdullah Specialized Children's Hospital
KIMARC	King Abdullah International Medical Research Center
MNGHA	Ministry of National Guard-Health Affairs
PND	Prenatal Diagnosis
SPSS	Statistical Package for Social Sciences
TOP	Termination of Pregnancy

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Declaration of conflicting interests

The authors of this article have no affiliations with or involvement in any organization or entity with any financial interest or non-financial interest in the subject matter or materials discussed in this manuscript.

Ethical approval

This study was approved by the Institutional Review Board at King Abdullah International Medical Research Center (KIMARC) (Study number: RC19/109/R).

Consent for publication

Informed consent was obtained from the parents.

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